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Workshop Report:

Oral health needs assessment world-wide in relation to HIV. Themes: Oral health needs and inequalities, oral health promotion, co-ordinating research and enhancing dissemination in relation to HIV.

Running title: Oral health needs assessment world-wide in relation to HIV

Keywords: HIV/AIDS; Needs; Health Services Research; Inequalities; Methodology; Health Promotion

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Abstract

Objectives. Review the meaning of 'health need', consider oral health inequalities and oral health promotion among people with HIV and outline methods to enhance co-ordination, standardization and dissemination of research efforts.

Methods. This workshop involved a brief introduction of each topic by an invited speaker followed by participant discussion. Participants were dentists and dental students attending the 7th World Workshop on Oral Health & Disease in AIDS

Results. A health need was regarded as a population's ability to benefit from care. Oral health inequalities called for both down and upstream health promotion. A community health programme to reach people with HIV infection in the community was described. Despite deploying community health workers to reduce costs the programme required additional resources for comprehensive implementation. The Indian National AIDS Control Program was exemplified co-ordinated efforts. Knowledge transfer can be achieved via educational, linkage and exchange and organisational interventions. Stakeholder engagement in a combination of all three types of intervention is the most effective.

Conclusions. The discussion centred on the difficulties of Indian dentists who felt they did not receive sufficient revenue to treat patients with HIV. An opposing view approach treated all patients using universal standards of infection control. Dental regulatory bodies, professional organisations and governments may need to demonstrate leadership and advocacy for the oral health of people with HIV infection.

Oral health needs assessment world-wide in relation to HIV. Themes: Global Inequalities & Improving Research Methodology

This workshop took place among the delegates at the 7th World Workshop on Oral Health & Disease in AIDS between 6th-9th November, 2014 in Hyderabad, India. The workshop considered the oral health needs of people with HIV. Two themes were addressed by the speakers: global oral health inequalities and the ways in which research methodology could be improved to enhance understanding in this field. Specifically, the five questions opened up by the speakers were:

1. What is an oral health need? Professor Peter Robinson
2. Global inequalities: Oral health and HIV. Professor David Williams
3. Oral Health Promotion for people with HIV Dr.Lucina Koyio
4. How can we co-ordinate research efforts and standardize research protocols in resource-poor countries? Dr. K. Ranganathan
5. How do we enhance dissemination of information and research findings Dr. Kiran Kumar Kattappagari

1. What is an oral health need? Professor Peter Robinson

HIV infection is often said to represent a special need in relation to oral health. Therefore conceptual clarity about the definition of 'need' was regarded as fundamental to the remainder of the workshop. Although a number of ideas of need exist, a particularly helpful definition in this context is to regard need as 'a population's ability to benefit from care' (Culyer, 1995)

Implicit in this definition are two important points; that there should be an underlying health problem, and that there should be an effective treatment for that problem. Many years of epidemiology have taught us about the prevalence of HIV-associated oral diseases, and in addition people with HIV often experience the same oral conditions as everyone else. Thus, the first point is frequently met in groups of people with HIV infection.

The second point is not so easily satisfied. Some conditions, whether HIV-related or not, do not need treatment. Clearly it is a waste of resources to provide care that will not bring benefit to the people affected. This point also calls into the question the idea or 'relative need'. Whilst some conditions may benefit from care that may not be severe, or may progress so slowly that they will not affect people during their lifetime, in which case the benefit that may be brought about by care is also limited. This limited benefit can be contrasted against the more profound benefit that can be delivered by effective treatment for a more severe condition, in which case there is greater relative need. However, needs assessment and healthcare planning at the level of the population must consider the total burden of disease and need. It may be that a 'mild' disease that is very common (such as dental caries) can cause a greater total burden than a severe disease that is uncommon (Marcenes et al., 2013).

The other aspect of the second point is that the treatments must be effective. That is, they should halt the disease and/or reduce its impact. The 'need' in question is therefore the need for *health*. Although this need might be expressed in terms of the number of treatments or the amount of dentist time, these inputs must demonstrably deliver benefits to health. This observation

highlights the continuing dearth of data on the effectiveness of treatments for oral conditions in people with HIV infection in resource-poor settings.

There are two further aspects of need that should be considered with respect to oral health in HIV infection. The first is the issue of how much need should be met? There is not a health economy on the planet that can meet all the health needs of its population, and therefore any needs assessment must determine how much of the need it can realistically afford to meet. The second aspect relates to the way in which we quantify the need. We have seen that 'need' is most readily expressed in units of treatment or staff time, but our emphasis on health means that these process measures must be supplemented with person-reported outcomes that measure health from the perspective of the persons concerned (Robinson et al., 2014).

Even this short introduction shows the importance of need in planning health care and health research. It also highlights key areas particularly relevant to this meeting. Our epidemiological research must be supplemented with assessments of the impact of oral conditions on the daily life of those affected so that we can identify the greatest health needs. We still need more evaluations of treatment, especially in settings that lack resources, and those evaluations must determine the effect of treatment on the people themselves, as well as on their clinical status. Very little evaluative research has been conducted with people with HIV infection using patient reported outcomes. Next, given the necessity of rationing care according to realistic and relative need, sophisticated health economic studies are required to identify the conditions that cause the greatest burden in the population and to determine which interventions deliver the greatest benefit for the lowest cost. Again, little such work has been conducted in relation to HIV.

The next presentation on global inequalities raises crucial moral and ethical concerns that supplement those introduced here.

2. Global inequalities: Oral health and HIV. Professor David Williams

We have yet to document whether there are oral health inequalities amongst people with HIV, but there are clear inequalities in the incidence of the underlying infection. Consequently HIV associated oral disease will add to the health problems faced by this group of disadvantaged people. The experience of our daily practice multiplied by the number of colleague's world-wide tells all dentists that poor oral health creates a major health burden on a global scale. This intuition is substantiated by the global burden of disease studies (Marcenes et al., 2013)

However, our growing understanding of oral health inequalities goes beyond this, to tell us that these headline figures mask differences in oral health. Major inequalities exist both within and between countries in terms of disease severity and prevalence. This is not simply a case of comparing populations with and without disease; there is a gradient of risk across the whole population.

The lower a person's social position, the worse their health. As a result, poor and disadvantaged populations have higher risks of disease and worse health. The prevalence of edentulousness is 18 times higher among people of the lowest social class than it is among the highest in the UK (Bernabe and Sheiham, 2014). Schwendicke and colleagues' (2014) systematic review brought together the results of 155 studies involving a total of 329,798 people. The odds ratio for having experienced caries (i.e. dmft/DMFT > 0) for someone with low educational or occupational status as compared to high status was 1.21. If parental educational or occupational status was

used as the indicator then the odds ratio was 1.48. This relationship was stronger in developed countries where caries can be seen as a disease of poverty.

The same disparities exist with relation to HIV disease. Low socio-economic status is linked, via risky situations and health behaviours to the incidence of the infection. Women of lower social standing are particularly at risk (Ickovics et al., 2002). These data move us upstream of simple matters of individual lifestyles to consider the life situations of people that determine those lifestyles. Accordingly, the US Centres for Disease Control is committed to addressing HIV and social determinants to achieve health equity. As the guardian of, and advocate for oral health, it is the duty of dentistry to identify and solve this ethical problem within our sphere of interest, and the Global Oral Health Inequalities Research Network has called for oral health to be integrated with these broader movements.

Watt's (2007) framework is an integrated strategy that seeks to reduce inequalities by intervening both up and downstream (Figure 1).

INSERT FIGURE 1 ABOUT HERE

Chair side clinical prevention and health education will be familiar to all dentists, and it is a tiny step to extend these downstream approaches to other venues, such as schools and the media. The more upstream approaches appear more radical, but have greater scope to reduce inequalities as they act at the population level and at the determinants of health and do not require dental attendance. Such broader health improvement strategies include training other professional groups, developing communities so that they can tackle the determinants of health and focussing efforts on key settings, exemplified by WHO's Health Promoting Schools initiative. Further upstream still, fiscal, legislative and policy actions can be introduced at national or local levels. For example, the Scottish Government are considering introducing taxes on products containing sugar and councils have either taxed or restricted the availability of sugary drinks (Davidson, 2014; ScottishHerald, 2014; Dugdale, 2015)

Whilst social inequalities of access to health care have been demonstrated amongst people with HIV infection (Marx, 1997; Coulter, 2000), it remains to be seen whether social gradients of oral disease exist independent of the distribution of the underlying infection. Consequently, further research is needed to ascertain the nature of these relationships and to assess the effect of interventions to reduce social inequalities in health.

3. A Community Oral health promotion model for people with HIV infection: Lucina Koyio

Figure 1 arrayed health promotion interventions from downstream to upstream. This summary of a community health promotion model for people with HIV infection describes a downstream approach to reaching people with HIV infection in the community in Nairobi East district, Kenya using community health workers (Koyio et al., 2013; Koyio et al., 2014a; Koyio et al., 2014b). This type of community outreach may decrease inequalities in access to health care. To avoid the expense of using dentists, the intervention deployed trained community health workers (CHWs). The effectiveness of this approach could then be evaluated in a controlled pre and post-test study using retrospective clinical records analysis and prospective data. The primary objective was to assess the effect of a training program to increase the knowledge and competence of CHW's in the recognition of HIV related orofacial lesions (HROLs). The secondary objective was to assess whether more patients with lesions would be referred from the community to the linking health

facilities and whether diagnosis of the HROLs by Professional Health Care Workers (PHCWs) (nurses and clinical officers) would increase at the linking health facilities. Training was given to 410 CHWs working in 8 community units that were linked to the health facilities with PHCWs. Initial one-day training was supplemented with selected photographs of HIV-related oral lesions, testimonies from patients with HIV, role plays and bespoke educational materials such as posters and brochures. The CHWs gained competences and skills in educating the community on oral health care, recognition of suspected HROLs and to referral of patients with suspected HROLS to the health facilities.

Supervision and monthly meetings with the CHWs was used to thank them for their participation in oral health care, to remind them of their roles and to invite them to submit their monthly data to the referral health facilities. Monthly reminders were sent to the CHWs in the field using short text messages to their telephone, again, to thank them for their help, to remind them of their roles, and to invite them to submit their monthly data to the referral health facilities. The control group comprised 404 CHWs from 8 community units that were also linked to the 4 health facilities

Data collected three months before the training program assessed CHW's baseline knowledge regarding HROLs and other general oral conditions by means of a 40-item structured questionnaire administered to 815 CHWs in test and control divisions. Data on referrals made by the CHWs were extracted from clinical records and the baseline number of HIV-related oral lesions that were diagnosed by the professional health workers (PHCWs) clinical officers and nurses) at the health facility was also recorded.

All the pre-training assessments were repeated six months after the training. The training increased CHWs' knowledge and recognition of HROLs and referrals of patients with suspected HROLs to the health facilities. The number patients with HIV referred with HROLs rose from 28 to 646 in the intervention group compared to 38 to 48 respectively in the control group. Thus the the training program increased access of HIV patients to oral health services (patients' education, recognition of suspected HROLs and referrals to the health facilities for care) at the community level.

However, more than 71% of the patients with suspected HROLs who were referred by CHWs did not visit the health facilities for care. Barriers to access could be attributed to predisposing factors among patients and enabling factors related to the health system. Patient-related barriers were attributed to patients' refusal to low HIV risk perception among patients with HROLs. A second barrier was fear of discrimination, as HIV infection is a stigmatized disease in Kenya. The third barrier involved community misconceptions about (HIV related) oral diseases, particularly oropharyngeal candidiasis (OPC). Almost 30% of CHWs related OPC to witchcraft, gastrointestinal disorders, sugary or hot foods and consumption of milk. These barriers often resulted in patients' seeking traditional remedies.

Health system barriers arose centrally but were experienced at the health facility level. Over 65% of those who received care at the health facilities did not go to the laboratory for a HIV test. High PHCWs' workloads averaging to 60–100 consultations per PHCW per day restricted the consultation time for each patient. The PHCWs therefore could not conduct HIV tests but referred their patients to the laboratory instead. Patients opted out of a HIV test due to the long waiting time and stigma from patients in the waiting bays.

The increasing oral health needs of HIV patients cannot realistically be met by the present dental health workforce within the current resource limitations. The CHWs' training program empowered the CHWs in community mobilization, patients' education and referrals patients with suspected HROLs to the health facilities at acceptable, affordable and accessible levels of care. However, successful implementation of this intervention requires additional PHCWs to address the identified barriers.

4. How can we co-ordinate research efforts and standardize research protocols in resource-poor countries? Dr.K.Ranganathan

As this workshop has identified, research, be it clinical or basic, has been an important tool in our fight against the HIV/AIDS pandemic. It is critical to inform early diagnosis, management and rapid responses to emerging infections in HIV infection/AIDS. However, given the quantum of research globally, it is imperative that these research goals are coordinated, both nationally and internationally, not only to address the morbidity of the disease in developed countries, but especially the morbidity and mortality in developing regions, where the major burden of the disease lies. This explosion in research in multiple institutes and governmental and non-governmental agencies (NGO), has also thrown up the need for standardization of research across borders, to make it relevant, reproducible and practically applicable.

Research needs to be both coordinated and standardized to address the coordinated needs of the affected population. This is imperative for management at the individual level and generating policies at the community, regional, national and international levels.

This would be possible only if the research ideas are developed with awareness of the local capacities and their ability to cooperate with different agencies and among themselves and involvement of all the stakeholders.

An example of this coordination and implementation which has been successful is the Indian National AIDS Control Program (2006) in its third iteration (NACP III) with an outlay of INR 115,850 million ($1.8Bn). The highlights of this successful program are that it can be adopted for oral health (or have an incorporated oral health component) and that it is reproducible globally, with modifications to address the regional issues as indicated in Figure 2. The program incorporates a framework for the allocation of finance within key objectives with targeted goals. All of the facets of this framework are achieved through an explicit policy of "Three ones" (One action framework, One Coordinating authority, One national medical and education system) and by working within a well-defined hierarchy under the one coordinating authority as shown in Figure 3.

INSERT FIGURE 2 ABOUT HERE

INSERT FIGURE 3 ABOUT HERE

5. **How do we enhance dissemination of information and research findings? Dr Kiran** Kattappagari

The dissemination of research findings is a crucial step in addressing the health, social, economic and educational implications of our research on oral health and HIV. It is therefore a core function of our work if it is to have impact. Unfortunately, even with effective transfer of knowledge we cannot assume implementation of research findings. Repeated studies indicate that dentists are relatively resistant to change (Elouafkaoui et al., 2015). Worse still, if we are to address wider societal problems such as population health and health inequalities we must work with policy makers in many sectors. In these cases the evidence-base that we provide will have to compete with alternate priorities and vested interests. The science of implementation is beyond the scope of this work but attention is drawn to specific texts and journals (for example see Brownson et al., 2012).

Knowledge Transfer (KT) is nevertheless a necessary precursor to implementation and should therefore be regarded as an explicit phase of any research project. Furthermore, by engaging the future users of findings into the process of research and dissemination, the possibility of implementation is increased. Models of knowledge transfer regard it as a dynamic and iterative process and apply frameworks or templates to assist in the practice (Ward et al., 2010; Strauss et al., 2010).

Of special importance is an explicit statement of the rationale for the project being disseminated. Different dissemination strategies will be required for objectives limited to increasing awareness and understanding, whereas those involving action require an implementation strategy that goes beyond mere dissemination. Implementation objectives should be set and external stakeholders who will be concerned with this implementation should form part of the Project Steering Group

KT strategies should also identify barriers to change and should link KT to those barriers. Knowledge can be transferred via educational interventions, linkage and exchange and organisational interventions. It is likely that a combination of all three types of intervention is the most effective.

<u>Educational interventions</u>

Each of our educational, research or dissemination projects will have an intended target audience. Therefore knowledge of the level of understanding and preferred means of communication for that target audience will assist dissemination and increase the likelihood of real change. Whilst different audiences may prefer to receive information in different formats, the content must be compatible and equally actionable across those audiences to prevent disenfranchisement of some groups.

Educational interventions might include:

- Dissemination events for stakeholders including.
- Workshops to support service development or reconfigurations in specific locations
- Reports and summary presentations specifically written for policy makers
- Reports and summary presentations to the relevant healthcare workers
- A summary report to patients and organisations advocating on their behalf
- Publication in open access journals

<u>Linkage and exchange</u>

Current approaches in many countries adopt participative approaches to working *with* stakeholders rather than simply disseminating *to* them. Stakeholders might include those who support our work; project staff, other colleagues and managers, but most importantly include lay groups and patients. Inclusive strategies of this type will ensure that stakeholders tell you (often quite spontaneously and in very certain language) about how they want to receive your message.

Participative approaches also require stakeholders to be able to question the message and receive serious answers to these questions. Whilst on the one hand this may appear to be time-consuming, open discussion of this type enhances communication; ensures that it is compatible with stakeholders' existing understanding (perhaps by changing that understanding) and increases the possibility of effective implementation.

There are relatively few patient organisations related to oral health, perhaps because oral disease is seen as ubiquitous and therefore unremarkable. However, the severity and stigma of HIV/AIDS often brings affected people together and such groups have been powerful advocates for those with the disease (see ACT-UP, 2015 for example).

One other reason for engaging with lay participants in this way, which is particularly appealing to researchers, is that it increases study quality. A recent systematic review found that involving service users in designing or running trials increased the likelihood of recruiting the samples on schedule by 60%. Trials with greater involvement were four-times more likely to recruit to target (Ennis and Wykes, 2013)

Linkage and exchange can result from incorporating stakeholders, patients and their advocates into Project Steering Groups and into the educational and organisational interventions. The Project Steering Group can be a powerful force for change as it can ensure that the dissemination is focussed on stakeholders' needs and in forms they can use. The Group can also use their networks for linkage and exchange. Other approaches to KT will be selected and tailored with the Group, in the light of ways in which the knowledge will be used.

Key opinion leaders should also be employed as part of the dissemination strategy

Organizational interventions

Organizational interventions can use relevant organizations and professional associations as knowledge networks. In the case of oral health and HIV infection these organisations will include dental organisations, research organisations such as the World Workshop on HIV infection, government departments as well as lay groups for people with the disease.

Discussion

Much of the discussion in this session focused on the expressed difficulties of primary care dentists in India treating people with HIV infection. This perspective focused on the large number of dentists in contrast to the relative affluence of the population and their (lack of) focus on oral health. According to this argument dentists do not receive sufficient revenue to be able to afford to treat patients with HIV infection, and therefore decline to do so. Proponents of this view did not indicate how they knew which patients were infected with HIV.

An opposing view was expressed very cogently by Professor Phumzile Hlongwa (Witwatersrand Dental School and Oral Health Centre, Johannesburg) where the experience is also one of low resources. However, the prevalence of HIV in South Africa is such that dentists have not been

able pretend that they are not treating patients with HIV. Instead they have long-since implemented universal standards of infection control. Not only is this approach more equitable towards people with HIV infection, it is more efficient and reduces infection with other agents that are more readily transmitted.

This discussion contributed to knowledge by disseminating these messages regarding universal levels of infection control to participating dentists. Further upstream, there is a role for the Dental Council of India, the Indian Dental Association and local and national governments to demonstrate leadership and advocacy for the oral health of people with HIV infection. These ideas were fed in to the Hyderabad Declaration made at the end of the meeting, which called for oral health care for people with HIV to be made universally and equitably accessible; free from prejudice or discrimination and evidence-based.

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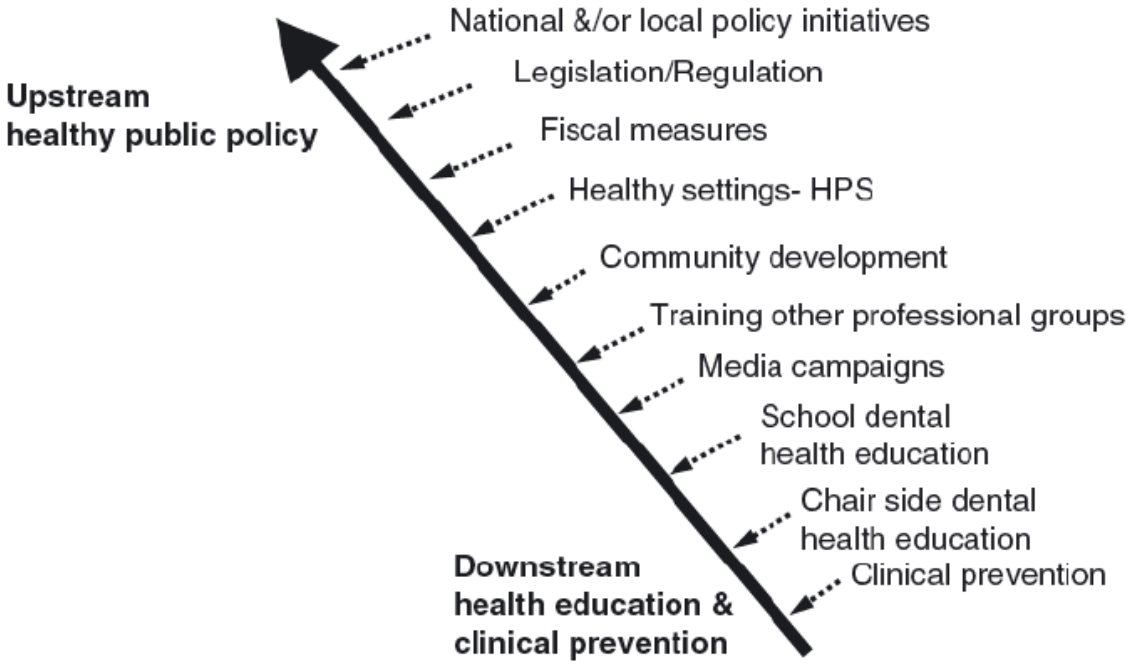

Figure 1. Up and Downstream Approaches for Oral Health (Watt, 2007)

Figure 2. Framework of the Indian National AIDS Control Program (NACPIII)

Financial allocation:

- Direct Governmental budgetary support
- External Aid Component
- Extra budgetary resource

Objectives

- Prevention
- Care Support and treatment
- Capacity building
- Strategic information management
- Contingency

Goals achieved

- Targeted interventions (behaviour change communication, condom promotion, referrals and care of high risk group)
- Link worker scheme (Intervention aimed at high-risk group and young population in rural areas)
- Counselling and test services
- Linking Anti-Retroviral Treatment (ART) centres
- District epidemiological profiling using data triangulation
- Information education and communication
    - Red ribbon express that utilises the reach of the Indian railways to disseminate information nation wide
- Monthly pension and travel and concession for people living with HIV and AIDS (to increases disclosure and voluntary testing)

Figure 3. Structure of the Indian National AIDS Control Program